

# Experiences and needs of people bereaved by epilepsy: Results from an online Australian survey



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## Purpose

People with epilepsy have a risk of premature death 2-3 times higher than the general population [1], with the risk of sudden death 20 times greater [2]. Deaths with no medical explanation may be classified as Sudden Unexplained Death in Epilepsy (SUDEP) [3]. Bereaved family and friends often regret that they did not realise death was a possibility, and ask if there was something they could have done to prevent the death [4]. This study aimed to explore the experiences and needs of bereaved family and friends prior to and following an epilepsy related death in Australia. Knowledge of these experiences can improve support for the bereaved and inform research on prevention.



## Method

An online survey was completed by adults who have lost a family member or friend through an epilepsy-related death in Australia. The 28-question survey, advertised nationally by epilepsy associations and research registers, was available between July 2012 to October 2013. Questions sought information on:

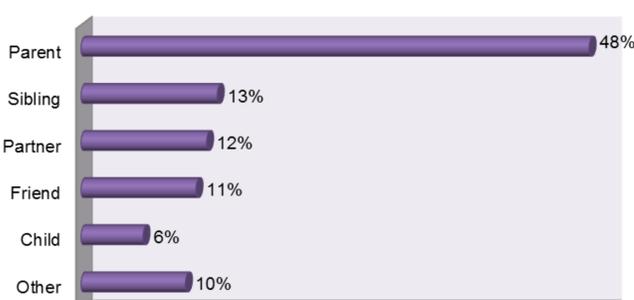
- the demographic details of the person with epilepsy
- epilepsy status and treatment
- time since the death
- satisfaction with service providers involved at the time of death
- follow-up support received
- perceptions on how well the death was explained
- and gaps and recommendations for services and support.

Quantitative data was analysed using SPSS20, with qualitative comments coded collaboratively by two researchers using NVivo10. Ethics clearance was obtained from Flinders University.

## Results

A total of 101 valid Australian responses by bereaved family and friends were received (Figure 1), describing 90 deceased individuals with epilepsy. The mean age at death was 32.1 years.

Figure 1: Relationship to the deceased (n=101)

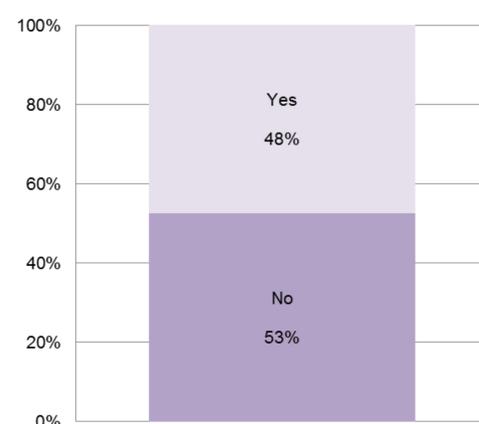


Further details associated with the death are provided in Table 1. Of note, over half indicated that prior to the death, they did not know people could die because of epilepsy (Figure 2).

Table 1: Details associated with the death (n=90)

Gender of the deceased	
Male	56%
Female	44%
Missing	15
Living arrangement of the deceased	
With partner/ family/ friends	79%
Alone	14%
Supported accommodation	7%
Missing	3
When did the death occur?	
<1 year	26%
1-5 years	41%
6-10 years	18%
>10	15%
Missing	2
Was the person alone at the time of death?	
Yes	58%
No	36%
Unsure	6%
Missing	1
Cause of death recorded (n=45)	
SUDEP	40%
Epilepsy	29%
Drowning	18%
Cardiac Arrest	4%
Asphyxiation	2%
Motor Vehicle Accident	2%
Unknown/Still waiting	4%

Figure 2: Prior to the death, did you know people could die because of epilepsy? (n=88)



“... I thought that it was only people who had very, very, bad, uncontrollable seizures and that it was constant fitting that could cause death (I thought this because it was never spoken about by any doctors). It was never explained to me that [name] could die of a seizure and how it could happen.” (#112; Parent)

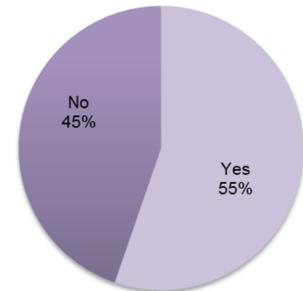
## Acknowledgements

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Nearly half of respondents (45%) felt the death had not been adequately explained to them (Figure 3).

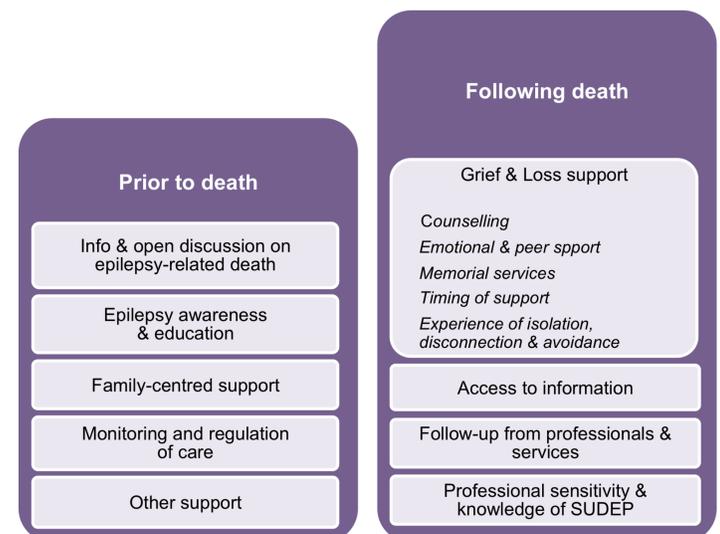
Figure 3: Do you feel the death has been adequately explained to you? (n=101)



“We now understand there are a range of possible contributing factors to the death and more research is needed to clarify the mechanisms involved. The neurologist offered his condolences but no other information or support.” (#68; Parent)

Respondents described both negative and positive experiences in support and services following the death, together with recommendations for future development. 137 comments were coded under two main themes, identifying the services and supports which should be available (a) prior to and (b) following the epilepsy related death (Figure 4).

Figure 4: Support and service themes



## Conclusion

Findings indicate family and friends were often unaware of the risk of epilepsy related death. Results underline the need to improve patient, family and professional education and participation in risk discussion (particularly relating to SUDEP); an approach endorsed by guidelines but lacking in clinical practice [5-6]. Results also highlight the value of both immediate and long-term epilepsy-specific information and support for the bereaved, from professionals, informal communities, and peer supporters. Future research must identify strategies to rectify the weaknesses in epilepsy services highlighted in this study.

## References

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